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Family-oriented multilevel study on the psychological functioning of adolescent children having a mother with cancer

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Abstract

Objective: This study aims to identify the predictive power of adolescents', parents', and illness characteristics on the functioning of adolescents when a mother has cancer.

Methods: Two hundred and seventy-one adolescents, 128 mothers with cancer, and 96 spouses completed standardized questionnaires 1–5 years after diagnosis. Stress response symptoms (SRS), internalizing and externalizing problems were assessed in adolescents. Parents' SRS, trait anxiety, marital satisfaction, and parent–adolescent communication were assessed in parents. Descriptive statistics and multilevel analyses accounting for non-independence of observations within groups were used.

Results: Descriptive analyses showed clinically elevated SRS in 20% of the sons and 30% of the daughters. Daughters experienced more internalizing problems than norm group girls. Multilevel analyses showed that adolescents' female gender and older age were associated with impaired child functioning. Higher levels of parents' trait anxiety and SRS, marital dissatisfaction, and poorer parent–adolescent communication were significant predictors also. Recurrent disease was associated with SRS and internalizing problems, and more intensive treatment with externalizing problems. Female gender and poorer parent–adolescent communication were overall the best predictors.

Conclusions: Having a mother with cancer may have far-reaching consequences for more than a quarter of the adolescent offspring. The multilevel approach of this study identified individual-level adolescent' risk characteristics as well as family-level risk characteristics for mental health problems. Adolescents at risk should be referred to health-care professionals specialized in working with families to help them to adapt to their parent's illness.

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Introduction

Parental cancer is a stressful experience provoking emotional and behavioral problems and stress response symptoms (SRS) in a significant number of children [1–3]. It remains unclear why some children develop psychosocial problems, while others seem to be doing well. Risk factors for increased problems may include characteristics of children, and also of parents as children are closely connected to their family system. From a family system perspective, mothers, fathers, and children affect each other directly and indirectly [4]. When a parent is somatically ill, coping capacities are

mutually influenced between parents and children as well as between the parental couple [5].

Gender and age are important child characteristics with regard to child functioning, in case of parental cancer. The majority of studies reported that adolescent girls are the most vulnerable [3,6].

The body of knowledge on the effects of family characteristics on child functioning grows steadily. Studies show that children may have more difficulty in adapting to the parent's illness, when parents have more emotional problems [7–10], are likely to react with anxiety in threatening situations [11,12], and experience marital distress [13–15].

Moreover, the quality of the communication between parents and children is an important predictor of child functioning when a parent has cancer [16–19]. The most common reason for poor communication between parents and children is that they do not want to upset each other [20].

Finally, illness-related factors may impact children's distress. A poorer prognosis and more intensive treatment were found to be related to increased problems in children [21,22], whereas treatment status, time since diagnosis, and the child's perception of illness seemed not [23,24].

A possible limitation of most of the earlier studies on the functioning of children of cancer patients is that children within the same family are seen as individual cases. However, they share certain family characteristics. Multilevel analyses may do more justice to children belonging to the same family. This study aims to identify the predictive power of adolescents', parents', and illness characteristics on the functioning of dependent children when a parent has cancer. Adolescents', parents', and illness characteristics will be included simultaneously into a multilevel family model to examine their unique contribution.

This study is part of a larger research project examining the psychosocial consequences for children who have a parent with cancer [2,7,16,22,25]. This paper differs from earlier manuscripts in that a family-oriented multilevel approach was used. Second, the sample of this study is different. Respondents who contacted us for participation were included in addition to the respondents who were invited to participate in the hospital.

Patients and methods

During a 2-year period, physicians or nurses informed all eligible cancer patients about the study at the University Medical Center Groningen (UMCG). Also, information was mailed to families who contacted the researchers following publicity to this study in regional and national newspapers and a documentary on television. Patients were eligible if they were diagnosed with cancer 1–5 years before study entry and had children between 4 and 18 years of age. They received written information about the study and an adapted version for their child(ren). Parents discussed study participation with their children. Informed consent forms were provided separately for each family member. When written informed consent was obtained from at least the ill parent and one child, researchers mailed a questionnaire to each respondent separately. Family members were asked to complete the questionnaire alone and not to discuss

answers with each other. The Medical Ethics Committee of the UMCG approved the study.

Measures

The Impact of Event Scale assessed SRS with respect to parental cancer of adolescents and parents. A weighted 4-point scale was used to rate the frequency of symptoms within the past week. Higher scores (range 0–75) denote more symptoms [26,27]. A score of ≥ 26 indicates clinically elevated SRS [27]. Cronbach's α in this study was $\alpha = 0.86$ for sons, $\alpha = 0.91$ for daughters, $\alpha = 0.91$ for ill parents, and $\alpha = 0.90$ for spouses. *The Youth Self-Report* (YSR) measured internalizing and externalizing problems in adolescents [28,29]. Problem items were rated on a 3-point scale. In this study, the raw scores of the internalizing (TIS) and externalizing scale (TES) were used. The TIS (32 items) consists of the syndrome scales withdrawal, somatic complaints, and anxiety/depression. The TES (30 items) consists of the syndrome scales delinquent and aggressive behavior. Higher scores on both scales indicate more problems. Norm values were available for a random sample of adolescent Dutch boys and girls (560 boys and 564 girls) [29]. Cronbach's α was $\alpha = 0.92$ for sons and $\alpha = 0.94$ for daughters for TIS, and $\alpha = 0.80$ for sons and $\alpha = 0.81$ for daughters for TES. The trait version of the *Spielberger State-Trait Anxiety Inventory* [30,31] measured proneness to anxiety of parents. They were asked how often a statement was applicable to them in general. They responded on a 4-point Likert scale. Higher scores (range 20–80) indicate more trait anxiety. Cronbach's α was $\alpha = 0.93$ for both ill parents and spouses.

The *Maudsley Marital Questionnaire-Satisfaction* measured marital satisfaction [32], which was defined as the subjective evaluation of the emotional connection with the spouse. Each item was measured on a 9-point scale (0–8). Higher scores (range 0–80) indicate more marital distress. Cronbach's α was $\alpha = 0.76$ for ill parents and $\alpha = 0.88$ for spouses. The *Parent-Adolescent Communication Scale* (PACS) was used to measure the parents' perception of the quality of the parent-adolescent communication [33,34]. In this study, the total scale of the PACS was used, a summation of the following two subscales. The subscale Openness of Parent-Adolescent Communication (10 items) assesses the quality of exchanging information and satisfaction about communication. The subscale Problems in Parent-Adolescent Communication (10 items) identifies barriers to parent-adolescent communication, i.e. presence of negative feelings about communication, absence of sharing feelings, and selectivity of subjects. Higher scores (range 0–100) indicate better communication. Cronbach's α was $\alpha = 0.82$ for ill parents and $\alpha = 0.86$ for spouses.

Medical information, such as diagnosis and treatment, was derived from patients' medical records. Parents indicated themselves whether or not they had recurrent disease. A dichotomous variable was created to compare children of parents who received surgical treatment alone with those of parents who received chemotherapy, radiotherapy, or multimodal treatment [2].

Statistical analyses

t-tests and chi-square tests were performed to analyze differences between the hospital and the external group and to compare psychosocial problems of children of cancer patients with those of a Dutch norm group. To assess clinical significance of differences, effect sizes (ES) were calculated using Cohen's *d*. An ES of 0.2 was considered as small, 0.5 as medium, and 0.8 as large [35]. Descriptives of parent and child functioning and *t*-tests were calculated to describe the study population. Descriptive analyses were also used to examine the prevalence of clinically elevated SRS in children (Table 1).

Multilevel analyses were performed to examine effects of adolescent- and family-level variables on child functioning simultaneously. Multilevel analyses are appropriate for data with nested sources of variability, because they account for non-independence of observations within groups, such as families [36]. The normal distribution assumption of the dependent variables was graphically evaluated by plotting histograms. SRS, internalizing and externalizing problems were not normally distributed. Therefore, in the multilevel analyses, Poisson distributions were used. The multilevel models were tested with the statistical package Latent Gold [37] to estimate variance in SRS, internalizing, and externalizing from the individual adolescent level (level 1, values of variables vary between siblings) and family level (level 2, values of variables are the same for siblings).

First, *null models*, without independent variables, were run as reference models. These models

estimate the variance in adolescents' functioning between adolescents and families. Second, characteristics of adolescents and parents (including illness characteristics) were included in a separate *family model*. Because ill parents' and spouses' trait anxiety ($r = 0.25$), SRS ($r = 0.29$), marital satisfaction ($r = 0.60$), and parent-adolescent communication ($r = 0.44$) were weak-to-strong correlated, parents' mean scores were computed.

Significance of effects (*Z*-value) was calculated by dividing estimates by its standard error. *Z*-values larger than 1.96 will be considered significant ($p \leq 0.05$).

−2 Log likelihood was computed to examine the goodness of model fit of the different models. Improvements in goodness of model fit between the null and family models were determined with the deviance test (likelihood ratio test) [38].

Results

Participants

In the UMCG, 467 families with children 4–18 years of age were approached by their physician or oncology nurse (hospital group); 110 families contacted us for participation (external group). In total, 205 hospital- (43%) and 89 externally recruited (81%) families consented to participate. Twenty-two percent of the hospital-recruited families that declined participation did this because of parental reasons (moved on with their lives, did not want to stir up emotions again); 20% because of the children (emotionally distressed, lack of interest); 25% gave various reasons (e.g. another illness in the family or were busy); and 33% did not specify a reason. The externally recruited families gave no explanations for nonparticipation. The ill parent's gender, tumor type, and time since diagnosis did not differ between consenters and decliners in the hospital group.

This study focused on families with adolescent children (aged 11–18 years) whose mother had cancer. Families of fathers with cancer were

Table 1. Descriptives of adolescents' and parents' functioning and *t*-tests for differences between scores of sons and daughters, and ill mothers and spouses

Instrument	Possible range	Sons	Daughters	Ill mothers	Spouses
		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
IES stress response symptoms	0–75 ^{ab}	16.1 (13.2)	21.1 (16.7)*	25.0 (17.6)	18.6 (14.0)
YSR internalizing problems	0–64 ^a	9.4 (7.2)	14.1 (10.5)**		
YSR externalizing problems	0–60 ^a	11.6 (6.9)	10.6 (6.4)		
STAI-T trait anxiety	20–80 ^a			39.4 (10.7)	35.4 (9.2)
PACS communication	0–100 ^c			72.1 (70.8)	73.2 (8.8)
MMQ-S marital satisfaction	0–80 ^a			15.6 (14.6)	11.7 (10.0)

* $p < 0.01$, ** $p < 0.001$ sons vs daughters.

^aHigher scores denote more symptoms.

^bA score of ≥ 26 indicates clinically elevated SRS.

^cHigher scores denote better parent-adolescent communication.

excluded in order to obtain a more heterogeneous study sample. The sample for this study included: 128 families with 271 adolescents (122 sons, 149 daughters, mean age 14.6 years (± 2.1)), 128 mothers with cancer (mean age 44.3 years (± 4.2)), and 96 male spouses (mean age 47.1 years (± 5.5)). In 39% of the families, one child participated, in 46% two, in 13% three, and in 2% four.

Mothers were diagnosed with breast (66%), gynecological (11%), dermatological (8%), hematological (6%), gastrointestinal cancers (5%), sarcoma (2%), and other malignancies (2%). The mean period of follow-up post-diagnosis was 2.6 years (SD 1.2 years). Twenty-seven percent of the mothers suffered from recurrent disease. Eighteen percent received only surgery and 82% received chemotherapy, radiotherapy, or multimodal treatment.

Descriptive analyses

Externally recruited adolescents reported more internalizing problems ($t = -1.99$, $p = 0.049$) and tended to report more SRS ($t = -1.96$, $p = 0.051$) than hospital-recruited adolescents, but groups did not differ in externalizing problems, age, and gender. Ill parents of the external group reported more trait anxiety ($t = -2.49$, $p = 0.014$) and were higher educated ($t = -3.52$, $p < 0.001$) than ill parents of the hospital group. As such group differences may cause bias when combining groups, the way of recruitment ('group') will be controlled in the multilevel analyses.

Twenty-four sons (20%) and 44 daughters (30%) reported clinically elevated SRS. The mean scores of the sons on the YSR were comparable to those of boys in the norm group (norm group TIS: $M = 8.6$, $SD = 5.8$; norm group TES: $M = 11.5$, $SD = 6.7$). Daughters had significantly higher mean scores on the TIS than norm group girls (norm group TIS: $M = 10.8$, $SD = 7.1$; $p \leq 0.001$, $ES = 0.4$). Their mean scores on the TES were comparable to those of norm group girls (norm group TES: $M = 10.0$, $SD = 6.1$). Daughters reported significantly more SRS ($p \leq 0.01$; $ES = 0.4$) and internalizing problems ($p \leq 0.001$; $ES = 0.5$) than sons. All ES in this study were medium (Table 1).

Multilevel analyses

Table 2 lists the results of the multilevel analyses, including adolescents', parents', and illness characteristics.

Stress response symptoms

On the adolescent level, gender was significant ($Z = -8.30$, $p \leq 0.001$) and on the family level, significant associations were found for trait anxiety

Table 2. Multilevel effects of adolescents' and parents' characteristics on adolescents' outcome

Predictors	Null model	Stress response symptoms	Null model	Internalizing problems	Null model	Externalizing problems
	2.93	3.34 Z value	2.47	3.60 Z value	2.40	3.87 Z value
		Estimate (SE)		Estimate (SE)		Estimate (SE)
Intercept						
Adolescents (level 1)						
Gender ^a		-0.337 (0.041)	≤ 0.001	-0.498 (0.054)	≤ 0.001	-0.045 (0.052)
Age		0.010 (0.009)	ns	0.018 (0.011)	ns	0.029 (0.012)
Parents (level 2)						
Trait anxiety		0.014 (0.004)	≤ 0.001	0.012 (0.005)	≤ 0.05	0.003 (0.005)
Stress response symptoms		0.011 (0.002)	≤ 0.001	0.003 (0.003)	ns	-0.004 (0.003)
Marital satisfaction		0.002 (0.002)	ns	0.019 (0.003)	≤ 0.001	0.006 (0.003)
Communication		-0.013 (0.003)	≤ 0.001	-0.023 (0.004)	≤ 0.001	-0.026 (0.004)
Group ^b		-0.143 (0.046)	≤ 0.01	-0.073 (0.059)	ns	-0.069 (0.062)
Time since diagnosis		0.011 (0.017)	ns	-0.002 (0.022)	ns	-0.040 (0.023)
Recurrent disease ^c		-0.218 (0.042)	≤ 0.001	-0.250 (0.055)	≤ 0.001	-0.004 (0.059)
Treatment ^d		0.029 (0.046)	ns	0.062 (0.069)	ns	0.140 (0.070)
R ² overall	-2262.19		-1440.90		-1024.97	
-2 log likelihood		-149.20		-705.29		-584.87

^aGender adolescents: 0, female; 1, male.

^bGroup: 0, hospital -recruited; 1, externally recruited.

^cRecurrent disease: 0, no; 1, yes.

^dTreatment: 0, surgical only; 1, nonsurgical or multimodal.

($Z = 3.68$, $p \leq 0.001$), SRS ($Z = 5.30$, $p \leq 0.001$), parent–adolescent communication ($Z = -4.69$, $p \leq 0.001$), and recurrent cancer ($Z = -5.18$, $p \leq 0.001$). The way of recruitment was also significant ($Z = -3.08$, $p \leq 0.01$). No significant associations were found for adolescent's age, marital satisfaction, time since diagnosis, and intensity of treatment. The variables in the model explained 23% of the variance in SRS. Female gender and parents' SRS were the best predictors.

Internalizing problems

On the adolescent level, gender was significant ($Z = -9.27$, $p \leq 0.001$) and on the family level, trait anxiety ($Z = 2.49$, $p \leq 0.05$), marital satisfaction ($Z = 3.31$, $p \leq 0.001$), parent–adolescent communication ($Z = -6.19$, $p \leq 0.001$), and recurrent disease ($Z = -4.54$, $p \leq 0.001$) were significant. No significant associations were found for adolescent's age, parental SRS, the way of recruitment, time since diagnosis, and intensity of treatment. Thirty-one percent of the variance in internalizing problems was explained by the variables in the model. Female gender and poor parent–adolescent communication were the best predictors.

Externalizing problems

On the adolescent level, age was significant ($Z = 2.48$, $p \leq 0.05$) and on the family-level, parent–adolescent communication ($Z = -6.77$, $p \leq 0.001$) and a more intensive treatment ($Z = 1.99$, $p \leq 0.05$) were significant. No significant associations were found for adolescent's gender, parental trait anxiety, SRS, marital satisfaction, the way of recruitment, time since diagnosis, and recurrent disease. The variables in the model explained 17% percent of the variance in externalizing problems. Older age and poor parent–adolescent communication were the best predictors.

The deviance tests (likelihood ratio tests) showed that the family models (stress response symptoms, internalizing and externalizing problems) improved significantly over the null models ($p < 0.0001$).

Discussion

The purpose of this study was to identify the predictive power of adolescents', parents', and illness characteristics on the functioning of adolescents 1–5 years after a mother's cancer diagnosis.

The descriptive analyses showed that daughters reported more internalizing problems than norm group girls, while sons did not significantly differ from peers. Twenty percent of the sons and 30% of the daughters suffered from clinically elevated SRS. This means they had an indication for professional

psychological support. High rates of SRS were also found in adolescent children of early-stage breast cancer patients and adolescents whose father or mother was recently diagnosed with cancer [1,25].

The multilevel analyses used in this study included both adolescent-level and family-level characteristics in one family model, to examine their relative contribution to adolescents' mental health problems.

Adolescent-level characteristics

Female gender was the best adolescent-level predictor of adolescents' SRS and internalizing problems. The emotional vulnerability of adolescent daughters has been shown by several earlier studies and may be related to increased household and care giving duties and, probably, to more emotional involvement with the parents [39,40].

Age was the best adolescent-level predictor of externalizing problems. The older the adolescents were the more externalizing problems they reported. It may be that older adolescents are more aware of their parents' feelings and that these, supposedly more sensitive, adolescents are more conscious of their parents' distress than younger ones. This greater burden seems to express itself primarily in behavioral problems.

Family-level characteristics

The psychosocial functioning of parents was a significant predictor of adolescents' SRS and internalizing problems. Higher trait anxiety levels in parents were associated with more adolescent-reported SRS and internalizing problems, but not with externalizing problems. It is likely that the anxious attitude of parents affects parenting negatively (e.g. overprotective behavior), which in turn may cause more anxieties and worries in children [41,42]. Moreover, SRS levels in parents were significantly related to SRS in adolescents. Interestingly, we found no significant relationship between parents' SRS and adolescents' internalizing and externalizing problems. In a European multinational study, parental depression was the most significant predictor of internalizing problems in children of cancer patients [9]. The association between parents' and child's SRS was also found in families confronted with childhood cancer [43,44].

In addition, parental marital distress expressed itself also in emotional difficulties in adolescents. Negative effects of marital distress on child functioning were confirmed by other studies in children of cancer patients and in children of parents with a stroke [15,45].

The parent–adolescent relationship was strongly related to both adolescents' emotional and behavioral functioning. Poorer communication between parents and adolescents was associated with SRS, internalizing and externalizing problems, and was

the best family level predictor for internalizing and externalizing problems. This suggests that parent–adolescent communication needs to be encouraged and, if families perceive barriers, they may benefit from support to improve openness and decrease specific communication problems. However, achieving open communication in families of cancer patients is a huge challenge, because children do not want to upset their parents and *vice versa*. Moreover, the coping attitude of parents may play a part in the way they communicate with their children about cancer [20].

Time since the parent's diagnosis did not play an important role in adolescent functioning, which is consistent with results from earlier studies [23,46]. That intensive treatment was in particular related to externalizing problems and recurrent disease in particular to SRS and internalizing problems was a surprising finding, which warrants further examination. Increased emotional problems were earlier found in children of parents whose health status deteriorated [21,47]. It may be that when a parent's cancer relapsed, adolescents realize that the chance they will lose their parent is increased and that this causes distress. An earlier study from our research group showed that adolescents may experience more barriers in the communication with parents in case of recurrent disease, and that these barriers are associated with more distress [16].

Finally, this study showed that self-referred adolescents reported more SRS and internalizing problems than hospital-recruited ones. Moreover, the self-referred ill parents had higher levels of trait anxiety than ill parents of the hospital group. The multilevel analyses showed that the way participants were recruited was a significant predictor of adolescents' SRS. Our findings underline that if participants in studies are recruited from different sources, they should not be considered as equal. Researchers should bear this in mind to prevent selection bias.

This study showed that 70–80% of adolescents were doing well, following diagnosis and treatment of cancer in a parent. With this multilevel study, we solved a part of the puzzle concerning the identification of vulnerable children of cancer patients (17–31% of the variance in child functioning was explained). Further research is recommended to explore the predictive and unique effects of other adolescent- and family-level predictors of child functioning, such as peer and sibling support, coping strategies used, quality of parenting, and the presence of other major negative life events in the family, to gain more insight into risk and resilience factors of children confronted with a parent with cancer.

Important strengths of this study were the data from multiple informants and the use of multilevel analyses in our two-level dataset. The multilevel analyses controlled for non-independence of

observations in siblings, and allowed integrating data from adolescents and parents simultaneously. These analyses were the first step in the multilevel approach of our data. Further studies are needed to examine more complicated multilevel models, with cross-level interactions between adolescent- and family-level characteristics and random slopes.

This study has a number of limitations, which need to be taken into account. First, the cross-sectional design of the study precluded the evaluation of the effects of parental characteristics on child functioning over time and causality; therefore, longitudinal studies are recommended. Second, the response rate of the hospital group was low (43%), in contrast to the response rate in the external group (81%). Although low response rates are common in questionnaire studies, it is possible that the hospital sample is not representative. Considering the reasons for nonparticipation in the hospital group, ranging from 'cancer is something of the past' to 'cancer still provokes strong emotions', problems might be overreported as well as underreported. Third, this multilevel study examined only the predictive power of variables related to the functioning of adolescents who had a mother with cancer, and should be further studied in adolescents who have fathers with cancer. Fourth, the sample was heterogeneous with respect to disease type and prognosis. The relationship between disease severity and child functioning should be further explored.

Conclusions

The descriptive analyses of this study indicated that, although many adolescents seem to adjust well to cancer in their mother, more than a quarter suffered from severe mental health problems. The multilevel family models showed that mental health problems were associated with characteristics of the adolescent (female gender and older age), parents (more SRS, higher trait anxiety, marital dissatisfaction, and poorer parent–adolescent communication), and illness (intensive treatment and recurrent disease). The multilevel approach recognizes that adolescents are nested within their family. Therefore, multilevel analyses seem to be the most suitable technique to study the functioning of adolescents (with their characteristics) in their family (with their own characteristics).

If indicated, adolescents should be referred to health care professionals specialized in working with families, to help them adapt to their parent's illness.

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